



November 10, 2011

The Honorable Geoff Davis
Chairman
Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Representatives
Washington, D.C. 20510

The Honorable Lloyd Doggett
Ranking Member
Subcommittee on Human Resources
Committee on Ways and Means
U.S House of Representatives
Washington, D.C. 20510

Re: Hearing on Supplemental Security Income Benefits for Children," Oct 27, 2011

Dear Chairman Davis and Ranking Member Doggett:

Thank you for the opportunity to submit a written statement following the October 27, 2011 subcommittee hearing on the children's SSI program.

Greater Boston Legal Services(GBLS) is a non-profit corporation that provides civil legal services to eligible low income clients in 33 cities and towns in eastern Massachusetts. The help it offers ranges from legal advice to full case representation, depending on client need. As part of its mission, GBLS, through its Disability Benefits Project, has represented children with severe disabilities since 1982. In 2007, the Children's Disability Project (CDP) was founded to offer more specialized representation to children in need of these benefits. CDP now assists vulnerable low income families at all levels of the SSI appeals process. CDP works closely with doctors, therapists, and teachers to present the full picture of a child's disabilities to the Social Security Administration. CDP's dedication to our young, vulnerable clients and skilled legal advocacy has garnered local and national recognition. CDP also works with *pro bono* counsel on these cases.

The Disability Law Center (DLC) is the Protection and Advocacy agency for Massachusetts. DLC is a private nonprofit entity that provides free legal assistance to individuals with disabilities throughout Massachusetts. A key mission of the DLC is to help ensure that people with disabilities are able to access the items and services they need to live and work in the community. Access to cash disability benefits and the associated medical coverage is crucial for many to achieve this goal - whether the benefits are needed for a year or longer term or episodically. Since 1983, the Disability Benefits Project (DBP) at the Disability Law

Center has provided technical back up and support to legal services advocates and private attorneys who represent individuals before the Social Security Administration (SSA). DBP supports high quality representation and advocacy for those seeking Social Security and SSI benefits.

The SSI program is a critical lifeline for the families of our young clients. As *The Boston Globe* reported yesterday, “[p]overty has deepened in Boston’s poorest neighborhoods, widening the gap between the city’s wealthiest and neediest residents,” citing a just released report. The study points to concentrated need in Dorchester, Mattapan, and Roxbury (Greater Boston neighborhoods), where 42 percent of children live in poverty, the densest cluster of childhood poverty in the state, according to the study sponsored by the Boston Foundation.”¹ Families caring for severely disabled children are at greater risk for poverty and privation.² This is what the low income families and children with disabilities served by GBLS face. Our advocacy helps families care for their children with severe disabilities at home. The SSI benefit is low but time and again we have seen that it can make a crucial difference.³

“Michael” is a twelve year old child who has been medically diagnosed as having Attention Deficit Hyperactive Disorder (ADHD), Anxiety Disorder, and a learning disability. His claim for SSI benefits was only approved after an in-person hearing with an administrative law judge. The independent medical advisor present at the hearing found that Michael’s combination of impairments functionally equaled listing level impairments. Michael and his twin brother are being raised by their elderly grandmother, who adopted them after their mother died of cervical cancer. They were born prematurely and Michael’s birth weight was under five pounds.

Throughout his young life, Michael has received services to help him develop and function. His grandmother has worked hard to see that he gets what help he needs. Some services he has received include: Early Intervention, therapeutic treatment, and medication. At school, Michael is in a substantially separate Supportive Academic Remediation (SAR) classroom. He is also helped at the School Achievement Clinic (SAC) at Boston Medical Center. SSI benefits have improved the quality of Michael’s life. According to his grandmother, who is on a fixed income, the first thing that they did with the SSI benefits was to pay off the balance owed on a bed for Michael that she had placed on lay-away. Michael had been sharing a small bed with his twin brother because his bed was broken. Michael’s grandmother does not drive and uses only public transportation to get to all of his medical and school appointments. They have used the SSI benefits for transportation. This eases the worry about travel expenses versus food and clothing. She also uses some of the SSI to pay for Michael’s portion of the household expenses for food and rent. Michael’s grandmother has said: “Without SSI benefits I don’t know how we would have survived.” GBLS has let the family know that when Michael is

¹ “Poverty’s Grip Tightens in Boston, Study Says”, by Meghan Irons, p.1 *The Boston Globe*, November 9, 2011.
<http://www.bostonglobe.com/metro/2011/11/09/poverty-grip-tightens-boston-study-says/pUXW8N2DkeJg1TE73IG8mM/story.html>

² Susan Parish et al., 2008. “Material hardship in U.S. families raising children with disabilities.”

³ Most families are below the poverty line without the SSI payment, but above the line with it. Off the Charts blog, CBPP, October 26, 2011;
<http://www.offthechartsblog.org/ssi-benefits-vital-to-severely-disabled-children-and-their-families/>

older, he may be able to use the work incentives available to students to help with the transition from school to work.

As noted by the Bazelon Center in its testimony submitted to this Subcommittee on November 3, 2011, “[m]ental impairments are rightly the basis of a large number of SSI claims, consistent with findings that mental disorders are the leading cause of disability in children and that severe psychiatric disorders have some of the worst outcomes with regard to school completion rates and life-long health and economic status.” Testimony at 3. Our client “Robert” and his mother illustrate what this means in real life. Robert’s mother has been in and out of the work force, depending on the severity of Robert’s needs. Now 16, Robert has struggled his whole life. He lives with his mother, and his father is banned from seeing them by a permanent restraining order due to incidents of domestic violence towards his mother. Robert was not the target of this violence but he witnessed it many times. Robert’s mother has described him as sad almost all of the time. When he is sad, he won’t eat, won’t talk, loses sleep, is very pessimistic and has difficulty expressing his anger. He has often said that he wished he was not alive, expressing suicidal ideation every time he is upset. He will stay in his room and cry. Robert has had several psychological evaluations. He has been diagnosed as having Bipolar Disorder and Major Depression.

A major stressor for Robert is in school where there is a climate of bullying. Robert reacts to the bullying by being physically aggressive and the school has had a difficult time dealing with his behavior. Robert says: “If I get called a name, I get so aggravated, I can’t control it. I just snap.” A discipline record of October, 2007 to June 2008 reveals that Robert had detention or was warned or suspended 21 times. Finally, he was removed from school in April 2008 to be tutored at home. Robert’s mother had a job with the school system which she had to leave because she now had to supervise and care for Robert at home. Over the years she has been employed on and off, depending on Robert’s condition. At present, Robert is awaiting a 45 day evaluation in order to determine what kind of academic setting is best suited for him. His mother hopes that she can soon work again.

Over the years, Robert’s treating sources have searched for treatments to help him, trying different medications sometimes with disastrous results. Originally, he was on Abilify where he had cognitive blackouts. The Risperal gave him hallucinations. He was then started on Lamictal, taken in association with Lithium. Lithium made him angry, so he began a treatment of Lamictal solely, with good results. Later, Robert was put on a generic form of Lamictal where he suffered side-effects of vertigo, dizziness and visual and tactile hallucinations. He had to stay out of school for a week for the medications to be out of his system. Robert’s mother wishes there other treatment options for her son but does not know what else to do, “I wish we never had to place him on medication because of the bad side effects on my child.”

Robert came to Greater Boston Legal Services four years ago for help with his SSI appeal. His mother has used the benefits for Robert in a variety of ways. For example, when Robert suffered from vertigo he had appointments at Children’s Hospital Boston twice per week. The cost of parking, tolls, and gas quickly consumed the family budget. She also uses some of

Robert's SSI to cover his portion of the household expenses for food and rent. Robert's mother has struggled for years to find a stable school placement for him. He has gone from public school to private school to home tutoring. His challenging behaviors in a school setting make it difficult to find the best setting for him. At present he is in a forty five day evaluation to determine what academic placement will best suit his needs. Robert's mother is hopeful that she can one day return to work full-time. According to Robert's mother: "If we did not have Robert's SSI, we would be homeless because I can't meet his needs on my own." Once he is settled in a school setting, GBLS will refer Robert to the local Work Incentive Planning and Assistance (WIPA) program for help understanding how he can use the SSI work incentives in his transition from school to work.

The SSI work incentives available to low income young adults with severe disabilities can be crucial in making a transition from school to self-sustaining work. "Jean" is a 20 year old diagnosed with a psychiatric disorder and learning disabilities who has a dream of working in criminal justice. As her condition is characterized with ups and downs, she will need a job with some accommodations in order to be self sustaining and will need education to get the type of job where these accommodations and health insurance are available. Luckily, Jean learned about the WIPA program and has been working with a WIPA Community Work Incentive Coordinator (CWIC) who told her about the SSI work incentives she can use, including the Student Earned Income Exclusion (SEIE) and the Plan to Achieve Self Support (PASS). Using these work incentives, Jean has been able to work part-time and retain necessary SSI and Medicaid coverage while attending college at her own speed. She is looking forward to completing her education and moving into a career.

Recommendations

We concur in the testimony and recommendations submitted by the Bazelon Center for Mental Health Law, and by Community Legal Services. We support Representative Richard Neal (D-MA) and SSA Commissioner Michael Astrue in their call for a study by the Institute of Medicine (IOM) concerning this program. Any changes made to this vital program must be evidence based. We support the effort by Congress to add funds to the SSA budget in order for the agency to be able to meet its statutory mandate to perform timely Continuing Disability Reviews (CDRs) on children. Unless funded, SSA cannot meet this mandate, which is a cost-effective way to maintain program integrity. We enthusiastically support all efforts to inform youth of the substantial work incentive programs that are available to them under the SSI program, as well as improvements to those programs. Finally, we oppose any effort to block grant the SSI program. Block granting SSI would cause countless children with severe disabilities to lose the benefits they need to be able to remain in the community with their families, and would result in escalating public costs in child welfare, public safety, juvenile justice and public-funded institutional care.

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Thank you for the opportunity to submit these comments.

Very truly yours,

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